The physical and psychosocial needs of acid burn survivors and the opportunities for support in Cambodia

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The final word goes to the special survivors. You have shared your darkest memories with us, for which we are indebted. We only hope that our study will draw its strength from you and thereby make an impact.

Nisha Thampi
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ABBREVIATIONS

ABS – acid burn survivor
ASF - Acid Survivor Foundation
WHODAS – World Health Organization Disability Assessment Schedule
NGO – non-governmental organization
ROSE - Rehabilitation Oriented Surgical Enablement
DAC – Disability Action Council
PWD – People With Disabilities
ABC – Association for the Blind in Cambodia
TPO - Transcultural Psycho-Social Organization
LICADHO: Cambodian League for the Promotion and Defense of Human Rights

INTRODUCTION

Background

Acid attacks are a particularly vicious form of violence that is prevalent throughout the world. This form of assault dramatically changes the life of its victim because of its debilitating and disabling impact on the acid burn survivor (ABS). With the primary aim of disfiguring the victims, the acid attack leaves them with permanent visible physical injuries, and serious psychological trauma.

Reasons behind Acid Attacks

Acid assaults occur around the world for many different reasons. The infliction of burns on women has been reported to be an ancient tradition in the Indian subcontinent (1). Reasons for assault differ throughout the world and frequently occur as a form of punishment or revenge for various perceived wrongdoings (1, 2). Other reasons include, but are not limited to, enmity of land properties, economics, criminal activity, family or land disputes, rejected marriage proposals and dowry demands. One common factor, in particular, that seems to account for a high incidence of the acid attacks is extramarital love affairs (3,4,5). In such situations, mistresses are sought out and attacked by suspicious or jealous wives, whereas the husbands are rarely the subject of revenge.

Impact of Acid Attacks

Acid attacks, while rarely fatal, have proven to result in serious morbidity. Physical lesions occur in the skin, tendons, articular capsules and other deeper organs. Parts of the body that are frequently affected include but are not limited to the face, neck, scalp, thorax and torso, upper and lower limbs, hands, eyes, eyelids, nose, lips, ears breasts and genitalia(1). Upon contacting the victim's skin, acid rapidly eats through the skin layers and penetrates the underlying fat, muscle, and even bone, if not washed off immediately.

Apart from causing severe physical disabilities, these injuries cause various aesthetic sequelae through disfigurement and permanent scarring (1,6) and lead to powerful psychosocial struggles. The attacks often result in a long and painful period of rehabilitation with severe facial disfigurement and visual impairment that cannot be easily concealed (5,7). Such factors often have a negative impact on social interactions, including loss of employment, education, and the opportunity for marriage, as scarred victims may be seen as outcasts in the community leading to social isolation and further problems(1). Damage to self-esteem and self-confidence, social isolation and ostracization, depression, post-traumatic stress disorders, and other psychological effects are common(4,5,7).

The issue of acid burns is further complicated by the problems of the minimal health care systems that exist in many parts of the world where the attacks are prevalent, and the cultural/political hesitancy to deal with these types of issues. Survivors of acid attacks are generally ignorant of first aid procedures following the attack(1), which leads to increased physical injury and susceptibility to infection. In rural areas, victims of acid assaults generally do not seek medical attention for their injuries, leading to burn contractures and many other

complications. In many cases victims are hesitant to seek medical attention because the injury is often considered as just punishment for a social transgression(1). If medical attention is sought, often in many areas of the world, there is a limited scope of resources with no reliable emergency burn unit comparable to the standards of Western medicine. The resultant cost of such medical care can be a serious drain on basic health services(8). Long delays in medical care further impede on the recovery process for many acid burn survivors(9).

Lengthy judiciary procedures, political shelter of the criminals, and the deterioration in general law and order have been identified as factors contributing to the increase in incidence of acid burns(3). Where studied, it was rare that the perpetrators were prosecuted(6) demonstrating tentativeness on the part of the judicial/political system to confront the problem of acid assaults.

Incidence of Acid Attacks

Assaults with chemicals is rarely discussed in the literature, even though it is a serious and devastating mechanism of injury and morbidity(6). Despite the frequency of acid attacks and the high traumatic acuity of each, acid violence is a little known phenomenon. What little is known has not resulted in substantially improved care nor a decreased prevalence of attacks(9,10).

Acid assaults have been reported in many regions and countries throughout the world, most notably in Bangladesh, where the issue has been researched and documented to a relatively large extent(3,5,9). Acid violence was initially thought to be a problem endemic to Bangladesh, however the attacks are now becoming increasingly identified in other areas of the world, including other Asian countries such as Pakistan, Nepal, Cambodia, Vietnam, Laos(9)and Hong Kong(4,7), as well as throughout the world, in Nigeria(11,12), Saudi Arabia(13) and Jamaica(8). Acid burns have even been reported as a mechanism of assault in various regions of North America, including Baltimore(14) and Dallas(15). The government of New Brunswick has identified acid burns as a common form of assault against women(16). In general, reports of acid attacks usually occur in regions of high population density, often with lower socio-economic groups(2). This trend, however, may be reflective of poor reporting within rural areas.

As acid assaults are being increasingly recognized as a global phenomenon, the issue is slowly becoming the focus of a small number of organizations that aim to assist acid burn survivors (ABSs). The efforts have focused on three major areas: judicial reform, public education/ advocacy and treatment of ABSs. Efforts to increase criminal penalties for acid attackers has been the prevention strategy used by the Regional Burn Center at the University of the West Indies(8). As well, it has been suggested that legal restrictions be put in the sale of potentially injurious chemicals(11), though this may not be feasible in many parts of the world due to lack of infrastructure within the law enforcement system.

Public education about acid burns has been centered around awareness of the harm caused by corrosive chemicals (7), and first aid procedures if acid does come in contact with someone's skin. In Bangladesh, where acid assaults have long been recognized, there are now organizations that deal directly and solely with the issue of acid burns. The Acid Survivor Foundation (ASF) and Naripokkho have a five pronged approach to countering acid violence: public awareness,

case reporting, short-term treatment, long-term treatment, and legal justice(9). ASF provides a variety of rehabilitation services for ABSs, focusing on all aspects of recovery, including medical treatment, vocational training, legal assistance and psychological rehabilitation.

Situation in Cambodia

As mentioned earlier, the strategic medical, psychological and psychosocial management of acid burn injuries is both challenging and complex, continuing throughout the long rehabilitation period(3). ROSEcharities, a surgical non-governmental organization in Phnom Penh, Cambodia, provides rehabilitation surgery for disabled people. In the area of plastic surgery, ROSEcharities has identified and treated many of these acid burn survivors through release of burn contractures. As well, ROSE performs surgeries for the correction of congenital deformities, facial tumours, and is one of the few hospitals in the country with the capacity to perform skin grafting for chemical and thermal burns, ulcers, and chronic open wounds.

Objectives

This study arose from the realisation that the surgical intervention by ROSEcharities was insufficient in addressing all the physical, psycho-social and vocational interventions for survivors of acid burns. Thus, our initial objective was to appreciate the impact of acid attacks on former ABS patients of ROSEcharities. With this knowledge, we sought to develop a network of communication and cooperation with local agencies that have the potential and resources to address the critical areas of the survivor's rehabilitation as a functional and integral member of Cambodian society. Thus, while the resources and capabilities of ROSEcharities are currently limited to surgical intervention, we hope that this document may help the organization guide post-operative acid burn patients to local organizations and groups that can address their complex psycho-social and physical rehabilitation.

METHODOLOGY

There were three main components to the research study:

1. Interviewing ABSs individually using a standardised questionnaire based in part on the World Health Organization Disability Assessment Schedule (WHODAS) instrument.
2. Holding a focus group with interviewed participants.
3. Meeting with key informants to appreciate the role of NGOs in addressing the issue of acid attacks in Cambodia.

We appreciated that, as with most translation processes, the integrity of the participant's responses may be compromised. In this regard, we sought out a translator interested in the research, and well-versed in medical terminology to appreciate the health issues that came up in each interview. In all three arenas, we thus enlisted the help of Ho Kunthea, a final-year medical student from Cambodia's only medical school, L'Université des sciences de la santé. Kunthea acted not only as translator but also as cultural interpreter, refining our objectives and questions so that they were culturally appropriate.

1. Individual interviews

The individual interviews were based primarily on the World Health Organization's Disability Assessment Schedule (WHODAS II). The complete questionnaire can be found in Appendix 1. Developed as an instrument to assess disablements, the WHODAS aims to "better understand the difficulties people may have due to their health conditions", in this case, injuries sustained from acid attacks. Each question was reviewed with our translator for clarity and appropriateness, and the scale was re-drawn to include Khmer lettering (see Appendix 2), as most individuals in Cambodia are more fluent with Khmer than English in speech and reading. The original WHODAS questionnaire can be seen in appendix 3.

The data was collected from ABSs who had been treated at the ROSE hospital, and visits were made to their community to appreciate their living standards and difficulties with daily activities. In addition to the WHODAS instrument, we also took each patient's case history, recorded their treatment strategies, and determined helpful mechanisms (individuals, institutions, treatments) in their recovery process.

2. Focus group

A focus group is defined as a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research (18). The main purpose of the focus group is to draw upon participants' attitudes, beliefs, feelings, experiences and reactions in a way which would not be feasible using one-on-one interviewing, and draw out multiple views and emotional developments within a group context (19). The topics are supplied by the researcher, but the insight and data produced by the interaction between participants distinguishes focus groups from group interviewing, where the emphasis is on individual responses to specific questions. The moderator's role involves promoting debate through open-ended questions, challenging participants to draw out differences in opinions, and keeping the session focused (19).

In the context of acid burns research, a focus group session was elicited at the exploratory stage of the study to explore issues and develop recommendations appreciable to humanitarian agencies. The information gathered from this group was helpful in understanding why certain issues, like psychological and financial impact, are salient to the post-operative care of acid burn survivors (ABSs). This forum was beneficial to participants, as they had the opportunity to be involved in decision-making processes and work collaboratively with the researchers. While some members were shy, the immediate feedback from the session was that it was empowering for all participants, with the chance to share and hear the experiences of other ABSs.

The invitation to participate in the focus group was extended to all ABSs who had been interviewed by the research team. Of these, 8 attended the focus group, and included two translators (Kunthea and another medical student). The questions focused on the following broad areas:

1. Their experiences being interviewed for this study
2. Sharing the acid attack experience
3. Impact of injury on family
4. Psychological problems following acid attack

5. What should be told to other NGOs on the behalf of ABSs

While areas 2 and 3 had been addressed in the interviews, it was hoped that the experience of exploring the incident with others who had undergone similar experiences would have therapeutic value unparalleled to the individual interview experience. Area 4 was addressed primarily because it was found to be lacking in the WHODAS instrument, but was nonetheless a critical issue in the follow-up care of ABSs. Responses elicited in area 5 were aimed to help towards the team's discussions with NGOs and in developing recommendations on how to address the issue of acid attacks effectively.

3. Key Informant Interviewing

Our third objective was to meet with NGOs in Phnom Penh to appreciate their role in addressing the issue of acid attacks in Cambodia. We determined which agencies to approach based on recommendations from ABSs and agencies initially interviewed, as well as a document prepared by the Disability Action Council (DAC) – Secretariat in 2001, entitled "Country Profile: Study on Persons with Disabilities (Cambodia)". This report gave a list of NGOs that were addressing issues concerning persons with disabilities (PWDs), which is arguably reflective of the physical status of an ABS. Thus, we sought to approach the following agencies and individuals:

1. Association for the Blind in Cambodia (ABC)
2. Bun Mao, Director of the Association for the Blind in Cambodia
3. Liz Cross, DAC Project Coordinator Medical/Rehab, Disability Action Council
4. Dr. Somney, Director of Burn Unit, Kossamak Hospital
5. Jason Barber, Consultant with Project Against Torture, Cambodian League for the Promotion and Defense of Human Rights (LICADHO)
6. Dr. Mok Theavy, Plastic Surgeon, Sihanouk (Russian) Hospital
7. Transcultural Psycho-Social Organization (TPO)

Of these, only Mr. Bun Mao, himself an ABS blinded by the attack, was unable to meet with the research team.

Quality of Data

There were limitations on the data acquired, and thus possible sources of error. While an international team developed the WHODAS instrument, certain questions had to be adapted to reflect the lifestyle of the Cambodian participants, including household chores, care of children and agricultural work. Moreover, many survivors were unable to walk more than 100 metres at a time, and yet the question specified the distance of 1 km. In addition, two of the questions (11 and 12) that are included in the WHODAS instrument were asked to only a few of the respondents. This was done because, during the initial interviews, the research team decided that these questions would be too difficult for most of the respondents to gage.

While helpful in gaining insight into the physical impact of the acid attack, the WHODAS instrument gave little to quantify the psychosocial impact on the survivors. We attempted to address this issue through the focus group session, yet the qualitative information gathered was only from those participants comfortable enough to talk about their emotions with the rest of the group and was by no means all encompassing. Moreover, the presence of a tape recorder during these sessions, to some extent, inhibited at least one of the participants from providing

information, who was embarrassed to have his opinions shared with the group as well as recorded.

Having Kunthea as translator was beneficial in developing a relationship with the participants, and yet posed potential challenges that arise with the process of translation. Her familiarity with the medical and social aspects of acid burns encouraged us to let her take the lead on asking questions and probing the responses. Yet, to ensure that the questions were sufficiently addressed, we asked that she translate each response before moving to the next question, thereby giving us the opportunity to further explore responses that may not have seemed particularly provocative to her.

A significant practical constraint was that the data was collected during a period of 3 weeks. Yet this time limitation was counterbalanced by a participant population that was selected based on its relationship with ROSE Charities, which made it easier for us to develop a positive rapport with them. These participants have been successful in seeking treatment for their acid burns, and thus represent a small proportion of acid burn survivors in Cambodia, most of whom are unable to access health and surgical services such as those offered at ROSE.

Our interviews with key informants were by no means exhaustive, comprising of agencies found only in Phnom Penh; there are known organizations elsewhere in Cambodia that are working with people with disabilities. We interacted with those that are strongly involved in addressing the long-term impact faced by acid burn survivors, as well as those who are only remotely aware and hardly engaged in the issues.

With this population bias and small sample size, one of the criticisms of our research study may be that of subjectivity. However, this work is not intended to provide a concise theory or refute another well-established understanding – the latter of which is not even evident in most parts of the world. Rather, this work is to provide a snapshot of the impact and perceptions of acid attacks by the individuals who have survived them, and key organizations that have the capacity to address them. Their experiences are reflective of some known aspects of acid burns already discussed. More importantly, the interviews with the thirteen acid burn survivors provide insight into the situation in Cambodia that extend beyond what is found in the literature.

RESULTS

1. Individual Interviews

Identification

A total of 13 individuals were interviewed. Eleven of these are acid burn survivors and two are fire burn survivors (with extensive burns, similar to those of the ABSs). The respondents who had been assaulted by acid consisted of five women between the ages of 21 and 26 years old; and six men between the ages of 16 and 37 years old. Additional data concerning the identification of the participants can be seen in table 1.

Table 1. Identification data of respondents from the study

Identification data	N
Living situation at time of interview:	
With Family (at least two members)	11
Independent	1
At ROSE	1
Marital Status:	
Single	6
Currently married	4
Divorced	2
Widowed	1
Education:	
No Schooling	3
≤ 5 years	2
6-12 years	6
College/university	1
Employment	
Paid work	2
Unemployed before assault	3
Unemployed because of attack	8

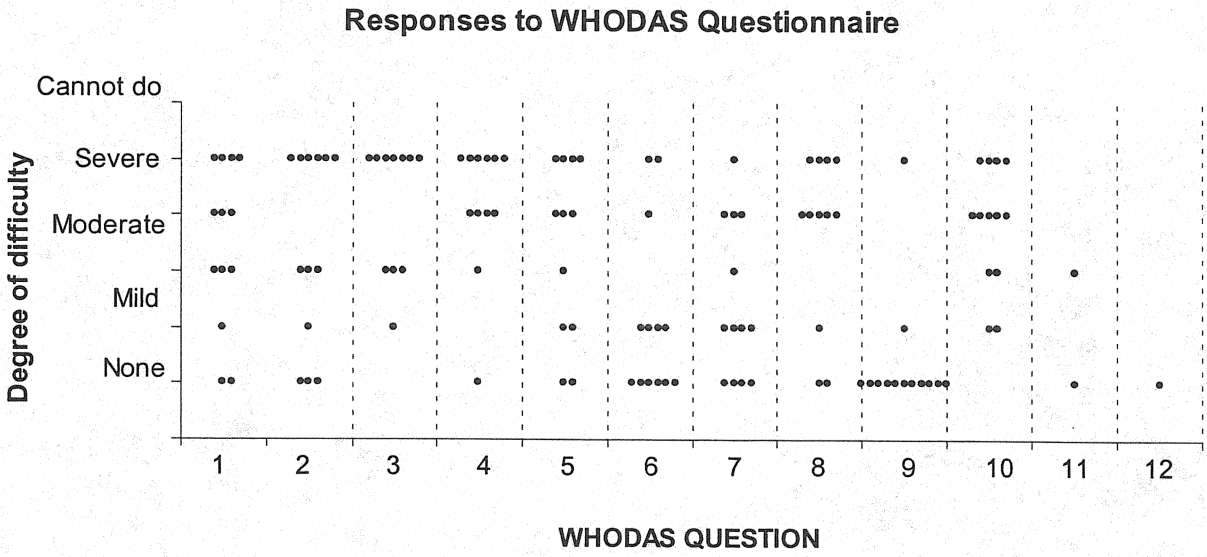
When asked how they would rate their overall health, responses were as followed:

Very good	0
Good	1
Moderate	7
Bad	3
Very bad	1

WHODAS

The results from all twelve questions on the WHODAS questionnaire can be seen in figure 1. The scatter plot shows the answers given by all of the respondents. If a question was not asked, which occured in a few instances due to various reasons, nothing was plotted on the figure.

Figure 1



Question #	How much difficulty do you have …
1	Standing for 30 minutes
2	Walking for 1 kilometre
3	Doing housework (cooking, cleaning, agriculture, taking care of children)
4	Working outside the home
5	Concentrating on doing something for 10 minutes
6	Washing your whole body
7	Getting dressed
8	Dealing with strangers
9	Maintaining friendships
10	How much do these difficulties interfere with your life?
11	Learning a new task
12	Joining in community activities

Other questions

Every respondent claimed that the injury interfered with their lives everyday. When asked "how has the burn affected your life, responses were varies and consisted of physical, psychological and social problems and difficulties. The problems and difficulties that were responded can be seen in table 2. If a certain response was repeated by more than one individual, the amount of repondents to this point is given after the point (ex: X3 means three people gave this answer). Four of the ABS could not carry out their usual activities at all in the last 30 days, whereas seven responded that theydid not need to cut back on their usual activities within the last month.

Table 2.

Physical	Psychological	Social
• More infections X3	• Disappointed X2	• Afraid of people

• Contractures X2 • Stiff • Tight X2 • Itchy X3 • Difficulty moving X2 • Opening mouth • Closing eyes • Pain X6 • Blind/partially blind X4 • Difficulty breathing • Photosensitive • Loss of appetite	• Depressed X4 • Sleeping problems X4 • Does not feel comfortable in body • Frustrated • Upset • Panic attacks	• Stay at home • Lost job/can't work X5 • Stay away from people X4 • Difficult to talk to people X2

The responses to the further questions that concerned the care that the respondents had received can be seen in table 3.

Table 3.

Location of care received	Medications/treatment	Who was helpful
Kossamak Hospital X11 Calmette Hospital X2 Health clinic	Medications for pain Medications for sleeping Compression bandages Skin graft I.V. X5 Vaseline gauze X2 Antibiotics X3 Transfusion	Family X12 Previous employer Friends X8 ROSECharities X2 Village community X2 Hospital staff X3 Community organizations X3

When asked if they had ever met any other acid burn survivors, 7 (of 12) responded that they had, most having met other ABSs at ROSECharities. Ten (of 11) respondents expressed a willingness and desire to meet other ABSs in Cambodia.

2. Focus Group

On Saturday June 21, 2003, the focus group session for acid burn survivors (ABS) was held at the ROSE Clinic in Phnom Penh. From 8:30am-11am, eight (8) ABS were able to share their experiences, words of encouragement and recommendations to humanitarian agencies within the country to address the issue of acid attacks. Details of the ideas and recommendations that came out of this gathering can be found at the end of the report. Presented here are the key findings and themes that emerged from this session.

Experience with interviews

The overwhelming response to the one-on-one interviews was positive as it appeared to be helpful towards socially reintegrating the ABSs through humanitarian agencies. Moreover, the interview was found to be encouraging to some respondents by recognizing their difficulties in daily activities. As noted by one participant:

> "[the interview] made me realise that society hasn't abandoned me yet. I am very happy that you met and spoke with me. Some people don't like me, but others like you still help and think of me. Every ABS wants to kill themselves, but today's meeting is helpful because we can meet other people with the same problems and learn how to cope with the injury."

Comparison of acid burn experience

Participants had the opportunity to share their stories of the acid attacks, as well as past medical history in addressing the burn injuries, similar to the question asked in the one-on-one interviews. There was mention of ROSE Hospital and LICADHO as sources of short-term care. The session elicited such interesting comments as "acid burn is 'better' than fire burn since fire is hotter," and:

> Khmer people's understanding of people with acid burns: they assume that the person acted indecently, for example a woman taking someone else's husband; or problems between couples. They speak ill of people with acid burns. I was on the radio and asked listeners to please change the idea that every ABS was attacked because of a "love problem" (patient 13)

Impact of injury on family

This session showed a significant impact of the acid attack on family dynamics and finances. In particular, some participants expressed their frustrations at being unable to work with the same efficiency as before (patient 03), or even at all, as was the case for patients 07, 11 and 13, who were blinded by the attack.

The participants also noted that the costs of treatment is "high in Cambodian society; if I had lots of money, then the doctor would see me" (patient 03). For many participants, after the burn, the family's economics "went down because we had to pay the money to treat [the patient]... [the injury] also had a great psychological impact on the family. The whole family feels sad... my family is poor because we've spent all the money on our son" (mother of a participant). The significant financial impact was reiterated by another ABS:

> High impact on family finances since I can no longer support family without a job. We sold the house to get treatment for my injury and moved into a smaller place. My mother was so upset with the injury that she couldn't work. But after the initial 2 years, the finances improved because my two younger sisters can work, and there is less treatment costs (before, it was $700/week plus costs for medicines). My younger siblings and father now get a salary and help support the family.

One participant, who had been the main breadwinner for her mother and siblings before the acid attack, is now supported by LICADHO by means of a small monthly stipend and accommodations in Phnom Penh.

Psychological problems following acid attack

This session arguably required the most sensitivity on the part of the moderator, and an increased sense of comfort and trust between the participants. Most of them were, however, willing to share in the psycho-social trauma that followed the acid attack and subsequent "loss of beauty". As seen below, the significant and long-term psychological impact of the event can be offset by meeting others who have been similarly disfigured and yet encouraging to other ABS.

> Right after the attack, I wanted to commit suicide because my beauty was gone. I was very upset because I could no longer see… But I was inspired after talking to other ABSs, especially [patient 07]. Now I feel better; I have to live – not for the other person, but for myself and for my society. I want other countries to know that Cambodian society has bad behaviours like acid attacks… I feel happy… I've also joined with other communities like the ABC, where I got to meet people like [patient 11 and patient 07]. My mental problems improved primarily through learning about Jesus, and secondly through my new friends at the ABC, who also encourage me.(patient 13)

> I wanted to commit suicide because I liked my face very much. After the first day, I wondered why I'd been attacked; I had done nothing wrong, I had no boyfriend or indecent relationship with someone's husband... it was unintended for me. Now I live for myself, regardless of whether the attack was directed to me; I want to prove to my perpetrator that I can live and will not die from the acid attack. I promised myself that I wouldn't die by my hands. Initially, I thought that I was the only girl who had such a bad problem. But after rejoining society, I realised there were others with the same problem, and felt better. I joined many communities and NGOs and met other ABS… I study Braille in English and Khmer at the ABC and home every night. Even the director of the ABC [Bun Mao] also has acid burns, but he can work as a director of a big community, which encourages me to struggle and become something like him. (patient 07)

Patient 01 had a less positive outlook on life.

> I feel very sad, it's so different from before. The world is changing now; I used to think the world was very beautiful. Even when I sleep, I have to cover my face because I don't want anyone to see my face. It's also difficult going out, so I don't want to go outside. Everything has been difficult since the burn. I only go out when the doctor calls me, or when my family encourages me to go out. I prefer to stay alone. If I go out, I will feel bad. Even when I see other people's hands, I feel upset because my hand was also injured in the attack. I don't feel bad being here because others have the same problems, but otherwise I don't like going out.

At this point, the interpreter and other participants tried to encourage her by pointing out that patient 13 has worse physical problems but better psychological state, but the patient retorted that people have different mindsets. Other participants described how their interactions with others have changed as a result of the disfigurement:

> I was depressed because I have a bad scar on my hand; I was handsome before the burn but now have a lot of scars. I cannot often meet other friends because I feel sad and ashamed of myself. (patient 02).

> Before the attack, everyone used to say that I looked handsome, but now that my beauty is gone, I feel very upset. When my friends come to visit me, I don't want to meet them. I want someone to help me repair my face so that I can look similar to a normal person. (patient 03)

The final respondent encouraged the other participants to rise above the loss:

> Every patient with an acid attack will feel depressed and hopeless. My parents tried to take care of my beauty ever since I was a baby, but now the perpetrator has damaged it through cruel behaviour… but after the treatment and because of family encouragement, we have hope to survive. Other ABS like [patients 07, 13] live in happiness and can struggle through difficulties with their physical problems. I admire them. We didn't anticipate the acid attack, and so could not escape from their murderous cruelty. Still, I feel sorry for the loss of beauty, because everyone loves beauty. For example, [patient 03] finds it very difficult to go out because people ask about the injury. I would encourage [patient 01] to not be upset and not ashamed to go out. (patient 9)

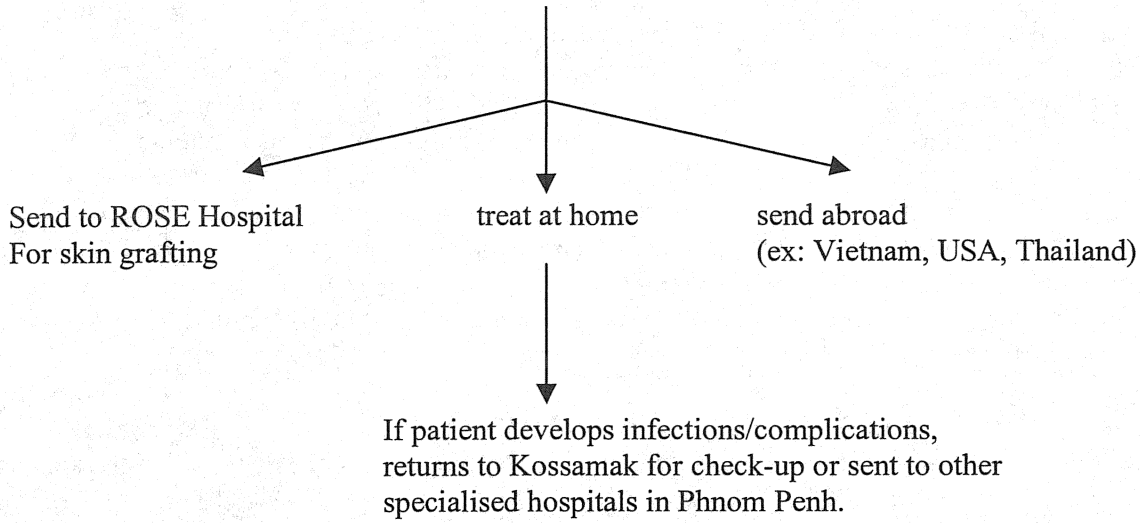
What should be told to other NGOs on the behalf of ABS

This session was helpful for the researchers in identifying salient issues to be addressed by organizations in Cambodia.

- I met a staff of another NGO, but in that organization, only visually functional clients are taught vocational skills and given loans and careers. The blind ABSs cannot benefit from this type of agency. Ask them why they can help individuals who have a handicap with their limbs, but not with eyes? I would like to find an NGO that can train the blind ABS… I approached the ABC to learn skills for massaging, but they would not teach me. I feel more discriminated than other persons with disabilities. When I approached a blind patient within the ABC, I was told that the client coming in for a massage would discriminate the blind ABS from other blind masseuses because of the burns. But I don't know if this is really the case because I've never had this experience. I feel the problem with discrimination by NGOs needs to be addressed before discrimination by normal people. (patient 07)
- After teaching a skill, the NGO should help find a suitable place for using the skill (ex: a job in a motor repair shop; a market to sell products of sewing). (patient 13)
- Help make my face look similar to that of a normal person (patient 03)
- I want an NGO only for ABS since it will be specialised to help find skills for them. ABS can do many things for other normal people once they have the skills (patient 09). This idea was supported by the other participants.

3. Key Informant Interviews

Dr. Somney, Director of Burn Unit, Kossamak Hospital
Hospital's method for acute burn treatment:
Burn injury → arrival at Kossamak Hospital → wash down patient → clean wound area → apply cream and cover with vaseline gauze (if the burn is deep) → stay at Kossamak Hosp's ICU for a few days → if the patient has no dyspnea and minimal pain, transfer to burn unit → [stay for 2 weeks to 1 month]



70% of patients develop keloids with ulcers, which are treated by steroidal injection; if no improvement, the keloid is excised. Burns are treated with silver sulfadiazine cream (Flammazine), which costs $4-5/bottle; the physician also prescribes antibiotics, vaseline gauze. For infected burns, Acid Flucidic Cream is used. Some patients prefer "neomécazole" (steroid and antibiotic cream), but this treatment leads to thickening and increased scarring of injured tissue. Kinétherapy (physiotherapy for the prevention of contractures) is also available at Kossamak. Interestingly, while Kossamak is a government hospital, patients must pay for hospital stay and treatment. Currently, the 400-bed hospital is treating 100 patients.

Association for the Blind in Cambodia (ABC)
Mr. Ma Samith, Office Administrator, informed that the ABC has worked with with 3 ABS. In fact, the founder of the ABC, Bun Mao, is also an ABS; he was not available for an interview. Jane Welsh, Management and Project Advisor with the ABC, was also helpful in providing information and resources on the ABC's response to blind women. The following summarises the interview with Ms. Welsh:

- ABC teaches Braille and English classes.
- New initiative: a women's subcommittee called The Cambodian Blind Women's Friendship Group; supported by Australia and an international women's group.
- Aim of the Friendship Group: "allow blind and visually impaired women to have a forum where they can discuss issues and experiences in safe and fun surroundings, gain access to skills and training, and to meet new friends."

- Monthly meeting for the visually impaired (though usually completely blind), including ABSs. Brings blind ABSs to Friends (an NGO in Phnom Penh) every Tuesday for facials, hand massages, etc. to increase their self-esteem and the opportunity to meet other young women.
- Ms. Welsh expressed an interest in helping more blind Cambodians, supporting ROSE's referral to the ABC of blind patients – both ABS and otherwise.
- Encouraged us to talk with Mr. Houer Sethul, a counselor with LICADHO who facilitates a counselling and support session with the participants [see key informant interview on LICADHO below].
- Provided us with written material received from ABC (enclosed in our report appendix).
  - Information on The Cambodian Blind Women's Friendship Group
  - Pamphlets on the ABC, including a list of its activities and contact information.

Liz Cross, DAC Project Coordinator Medical/Rehab, Disability Action Council (DAC)
Ms. Cross was initially reserved about the nature of our research, explaining that it is important the physician follow up on the patient's therapy outside the hospital, and with surgeons coming into Cambodia for a short period of time, the follow-up may be difficult at the same NGO. She stated that there are many NGOs in Cambodia addressing the issue of persons with disabilities (PWDs); the different areas of focus include working with the blind; physical rehabilitation. Moreover, there is an issue of resources available to patients from the provinces seeking treatment in Phnom Penh, and transportation concerns for long-term rehabilitation services.

DAC coordinates programs between NGOs, whose physical therapy services have moved away from Phnom Penh into the provinces, where most of the population in need are found. ABS have particular trouble getting involved in activities with other PWDs because of years of surgery and psychological trauma preventing them from interacting with others outside of their home. "And people are perceived as deserving what they got".

She listed the following as physical therapy resources:
- Veterans' International (at Kien Kleang)
- Cambodia Trust (although this is shutting down its services in the provinces)
- Handicap International in the provinces (also slowly closing down)
- International Red Cross (works in Siem Reap; Pailin)

The following are mental health resources that may be available to ABSs:
- TRANS-cultural Psychological Organization (TPO)
- International Organization for Migration (IOM) –centre in Russian Hospital.
- Social Services for Cambodia
- Centre for Child Mental Health (in Takmao): Dr. Bhoomi Kumar, Project Director with Caritas Cambodia 023-300-534

Cambodian League for the Promotion and Defense of Human Rights (LICADHO)
An interview with Mr. Houer Sethul, a counselor in the Project Against Torture program, and Dr. Chandara, physician at LICADHO, was helpful in learning about the agency's Project Against Torture. We learned from them about LICADHO's program:
Mandate - Human Rights Organization, promoting advocacy
Staff – all together in the 12 provincial offices, have over 100 staff.

Funding – from various International aid organizations

PROJECT AGAINST TORTURE

- LICADHO recognizes acid assaults as a form of torture; addressing the issue is a new initiative for the organization.
- LICADHO has worked with at least 2 ABS
- Aim to provide counseling for torture survivors (once per week), encouragement, support services for the survivors and their whole family, physical rehabilitation, food, accommodations, medicine and some help to seek employment (vocational training).
- As well, they give support with legal issues involved with the torture.
- For serious medical cases, and cases involving the law, patients are taken to government (municipal) hospitals for medical referrals, which LICADHO pays for. Simple cases are treated by Dr. Chandara and other medical staff at the LICADHO Medical Office.
- Issues that arise during counseling (patients' feelings after the burn):
  - Depression
  - Difficulty adapting to new physique
  - Discrimination by members of the community; strangers
  - Suicidal thoughts arising from destruction of beauty, hopelessness, nightmares, fear, helplessness.
- Counselor training: a consultant from another country teaches counseling skills specific to work with torture survivors. Mr. Sethul noted that there are only 2 counselors for the Project Against Torture.
- Part of goal is to contact other NGOs to participate in the psycho-social needs of "victim" and family.
- Asked if ROSE could refer ABS to LICADHO; Mr. Sethul asked us to send LICADHO the information concerning the patients, which they would assess and determine LICADHO's role.

The medical staff at LICADHO reiterated much of the information provided by Mr. Sethul and Dr. Chandara. They noted that ABSs are found via newspaper articles, individual reports, LICADHO provincial office. They also outlined the process for individuals in their program for accessing medical treatment:

- Children are taken to a World Vision organization
- Adults receive food, medicines, accommodations, vocational training (ex: sewing, motorbike repair) from LICADHO.
- Clients access medical treatments either with LICADHO's doctors or via referral to provincial/NGO hospitals.

A meeting with Jason Barber, a consultant with the Project Against Torture, was informative as he has been drafting a report on the issue of acid attacks in Cambodia, which looks at the causes and consequences of acid attacks that were reported in the Cambodian newspapers. His report, for example, gives a detailed account of Patient 11's story (which we did not get accurately during our interview), as well as some preliminary numbers of ABS. The report has some generalized comments, though not much concerning resources available for ABS in Cambodia. Mr. Barber also provided a report (one in English and one in French) written by Physicians with Medecins du Monde, concerning the treatment of ABS patients at Calmette hospital. This report

recounts the number of cases, and a brief general description of the problem and reasons behind the assaults (the French version is more informative than the English).

Dr. Sotheara Chhim, Psychiatrist and Managing Director, Trans-cultural Psycho-social Organization (Community Mental Health Programme in Cambodia)
TPO aims to promote psycho-social well-being, especially after decades of war and trauma, by empowering local resources. Dr. Chhim has found that communities have many individuals in a state of inactivity, hopelessness, psychiatric problems, high rates of alcohol abuse and domestic violence. While he gave an excellent overview of the organization, he did not specifically address the psycho-social impact of acid attacks on the survivor. In fact, when asked about acid burns, he was "not sure if they are a major issue", but stated that the TPO welcomes all types of people, including ABS and "even former Khmer Rouge soldiers", as the latter related to a recent project that the agency has begun in partnership with Document Center-Cambodia.

Dr. Mok Theavy, Plastic Surgeon at ROSE and Sihanouk Hospital, Phnom Penh
Dr. Theavy, a Khmer plastic surgeon, was trained in Phnom Penh and Belgium. He sees patients burned by fire, boiling water, acid, and does skin grafting and contracture release at Sihanouk Hospital and ROSE; other skin grafting centres in Phnom Penh are the HOPE Centre (another NGO), and the CSI whenever a foreign-trained physician comes into town. As the hospital is not a burn centre, Dr. Theavy sees a varying number of burn patients every month, although he tends to see 1 or 2 ABS each month. Patients seem to be usually attacked following a quarrel, and the burns are to the head, neck and arms. Most ABSs don't seek treatment right away, but rather come after developing contractures.

Dr. Theavy explained that acid burns go deeper and develop stronger contractures than fire burns, and therefore require immediate first-aid and significant surgical care. He appreciates the psychological problems facing ABSs, including loss of beauty; anger; sometimes loss of family. He has seen an increased incidence of acid burn issues, which result from decreased socio-economic stability (financial instabilities, increased incidences of quarrelling); corruption within the justice system that favours certain perpetrators. He felt it was important to inform ABSs that they can get treatment at Sihanouk Hospital, since many don't realise this.

He realises the difficulty for burn patient to stay in the hospital, namely financial, social costs, and thus finds it problematic to follow up with patients who live far away. He encourages patients to participate in physiotherapy or do it themselves if they live far away (therapy provided by Sihanouk; Veterans' International; Chesset Hospital; some provincial district hospitals ex: Battambang). Most burn patients are poor, and cannot afford the fee for treatment ($130 for a big operation; $100 for medium; $80 for minimal surgical intervention) and time in the hospital (3000 riels/day). The cost is therefore waived for the poorest of patients, defined as having no family, property, money (and therefore destitute), or NGOs are approached to help pay for treatment. He had an interesting idea of developing a system of "Friendship Hospitals" around the world, similar to the concept of sister cities. In this manner, a hospital in Canada can "buddy up" with Sihanouk Hospital and help defray costs for surgical instruments and equipment. It remains to be seen if Canadian hospital administrations will welcome this benevolent idea.

DISCUSSION

Relevance of the issue

Acid throwing, as a form of assault is a serious medical and social problem in Cambodia. Acid throwing is an available and utilized form of assault, with severe life altering consequences for the victims, both physically and psychosocially. These attacks are not isolated occurrence, resulting in extensive individual, community and societal burdens. Acid throwing as a form of assault has been reported in the media on several occasions in Cambodia. At least 44 acid attacks were reported in local newspapers in the three years between December 1999 and November 2002 (20). Rose Charities has reported 31 cases of acid burns requiring surgery between January 2000 and March 2003(21). The organization Médecins du Monde has reported treated 22 patients burnt by sulfuric acid over a ten year period in Cambodia(22). The actual number of acid burn assaults that have occurred in Cambodia has not been determined, due to various factors including the lack of proper medical care to people living in rural areas, and the lack of reporting of such attacks. Acid burn assaults continue to occur in Cambodia, therefore recognition of the problem is the first step in giving aid to this victimized population.

Complexity of the issue

Every acid burn survivor is different in terms of causes and consequences of their injury. Although the rate of mortality from acid assaults is quite low, the morbidity that results from these attacks is grave, manifesting itself in many forms. All ABSs struggle with a combination of physical, psychological and social disabilities, each to varying degrees. All these disabilities seem to depend on various factors, including initial and ongoing treatment, support network and socio-economic status. Though the mechanisms of assault are similar, the medical sequelae that result from the attacks are innumerable and can involve almost any part of the body. Because of this, there are countless combinations of treatment needed. A comprehensive and individualized rehabilitation strategy is necessary in order to provide proper care and treatment for acid burn survivors.

Physical impact

From many of the one-on-one interviews, the participants ascribed much of their limitations in daily activities to physical scars and injuries from the burn. These were often in the form loss of ability and movement (contractures, limited range of motion, loss of vision, difficulty breathing) as well as altered feeling in burned areas (pain, stiffness, tightness, itchiness).

The WHODAS questionnaire focused predominantly on physical disabilities. The WHODAS describes having difficulty with an activity as increased effort, discomfort or pain, slowness or changes in the way a person does an activity. Of the 12 questions asked 7 involved different physical tasks. Of these tasks, 4 were reported to be at least moderately difficult by more than 70% of the respondents. These include standing for 30 minutes, walking for 1 km, doing housework and working outside the home.

These findings show that, with respect to physical disabilities, ABSs have many difficulties with even the most basic of tasks, and these difficulties were found to be severe. This demonstrates that, upon development of individualized treatment strategies, effort must be taken to develop a substantial and appropriate physical rehabilitation regimen.

Psychosocial Care

The ABSs interviewed shed some light into the significant psychosocial consequences of acid attacks. At a personal level, these issues include suicidal ideation, destruction of self-esteem, depressed moods, and a changed outlook on life (some of which became more positive, whereas others were now negative). At a social level, most survivors found more difficulty in social interactions, and a general fear of strangers. The sense of shame is concomitant with a societal obsession with physical beauty, which many of the survivors noted as reasons for their lack of interaction with people outside the home.

Interestingly, the family played a role in addressing the psychological issues facing the ABS. On the one hand, family members shared the impact of the attack on the patient (with similar feelings of depressed moods, difficulty in adapting to the survivor's new physique, and the financial implications that arose from steep medical bills and loss of income from the victim, if he/she was an earning member). Yet the family can become a source of healing, encouraging the individual to survive the attack and live meaningfully. One survivor similarly found solace in religion; whereas her facial burns were arguably the worst we had ever witnessed out of the 13 participants, her outlook on life was one of the most positive and inspiring for other ABSs at the focus group session.

The importance of meeting other ABSs in the setting of a focus group was not lost upon the research team. There was, indeed, great therapeutic value to be gained in sharing stories, difficulties and insights for the survivors and their families, all of whom wished that there could be further opportunities for such meetings. One ABS who had followed the prescribed physiotherapy regime even demonstrated techniques to prevent contractures to other participants at the focus group. As for the research team, the focus group session provided us with the opportunity to gain further insight on issues that arose during the individual interviews, especially in the area of psychosocial needs.

Response to Issues Facing Acid Burn Survivors

Our results have identified a number of paradoxes in the capacity and actions of various local agencies in responding to the many issues facing ABSs. For one, the government's response seems to be negligible. In the case of Kossamak Hospital, the Burn Unit is eager to help treat all survivors of acid attacks, as it is the only government-run burn unit in Cambodia. The serious lack of professional and therapeutic resources, however, seems to be hindering this process, resulting in short-term "band-aid" solutions to an otherwise-long-term health problem. Thus, as is the case in many developing countries, the NGO community is filling a much-needed role in developing intervention programs where the government has limited direct resources. Their impact, however, leaves much to be desired as a survivor seeking long-term care and resources.

ROSECharities, a non-governmental agency, has more facilities and resources to provide treatment to survivors of acid attacks. In particular, they seemed to have gained confidence following the surgical care provided; even with contracture release and skin grafts, the patients appreciated that such a facility existed to address their unique needs. The response from its patients has therefore been overwhelmingly positive, as most of them see ROSE as a means of addressing the physical impact of the acid attack. The Association for the Blind in Cambodia (ABC) has also been helpful towards ABSs who lost their vision as a result of the acid attack. With a cooperative learning environment and a woman's support group, the agency has gone far in responding to their needs and providing them opportunities to reintegrate into the workforce. LICADHO was also helpful in providing short-term financial support, counselling, physical rehabilitation and vocational training. In addressing the legal context of the acid attacks, LICADHO provides a frame for retributive justice for the survivor. However, the agency recognises that its advocacy and activism approach are oftentimes lost on the general population and especially on the government, where a corrupt and inefficient judicial system has prevented a number of cases from coming to trial. There is renewed hope, however, with LICADHO's novel report on acid attacks in Cambodia, in which is described the causes and consequences of acid burns.

The responses from participants illuminated an interesting finding: while the psycho-social impact stemmed largely from the attack itself, its perpetuation was influenced by the responses of NGOs to their concerns. All the patients found the services at ROSE and LICADHO to be beneficial in short-term care. While the efforts of the ABC were similarly commended, some patients felt that they were being discriminated against receiving vocational training because of the potential impact of their horrific burns on clients.

Whereas some organizations are thus engaging with ABSs and have criticised the judicial inertia in addressing the root causes and impact of the acid attacks, others, such as the DAC and TPO, were more reserved in resourcefully tackling the issue. The DAC asserted that there were already few resources available to persons with disabilities across the country, and that long-term physical therapy for ABSs was especially difficult because of the necessary follow-ups required for the client's progress. TPO was equally vague in its appreciation of the psycho-social impact of acid burns on survivors; in fact, both agencies seemed to be unaware of the fact that acid attacks are increasingly prevalent in Cambodian society.

Thus, the response from the government and NGO community has been tepid and at times discouraging for the acid burn survivor. While there is recent mobilized interest in addressing the human rights violations, there remain poor outreach mechanisms and the practical issue of resource allocation when seeking to respond to other persons with physical disabilities or psychological needs.

RECOMMENDATIONS

Judicial reform

1) Cambodian criminal law does not mention acid violence, although it has been a growing phenomenon, especially within the last decade. While perpetrators can be charged with battery resulting in injury, there has been evidence of poor law enforcement. Advocates for acid burn survivors should look towards increasing the integrity of the judicial system, most notably in the areas of investigating acid attacks, arresting the perpetrators. Further efforts include strengthening the new draft law on domestic violence that punishes acid throwers so that it applies not only to family members but also to the general community. There should be a paralleled government commitment to financially support the survivor, which would counter the perpetrator's hopes of "paying off" the victim where the victim is poor and requires immediate money for burn-related treatments. Advocating for judicial reform has become more important with the evident judicial discrimination against female perpetrators (who have been found to receive longer sentences) and government officials (most of whom have been living freely since participating in the attacks).

2) Restrict the availability of strong, undiluted acid. We encourage LICADHO's recommendation of strictly regulating the sale of acids by requiring that sellers record the names and contact information of all buyers, and be otherwise prosecuted for violating this law. Such record- keeping is hoped to be helpful to investigators seeking to determine where the perpetrator obtained the acid.

NGO mobilization and collaboration

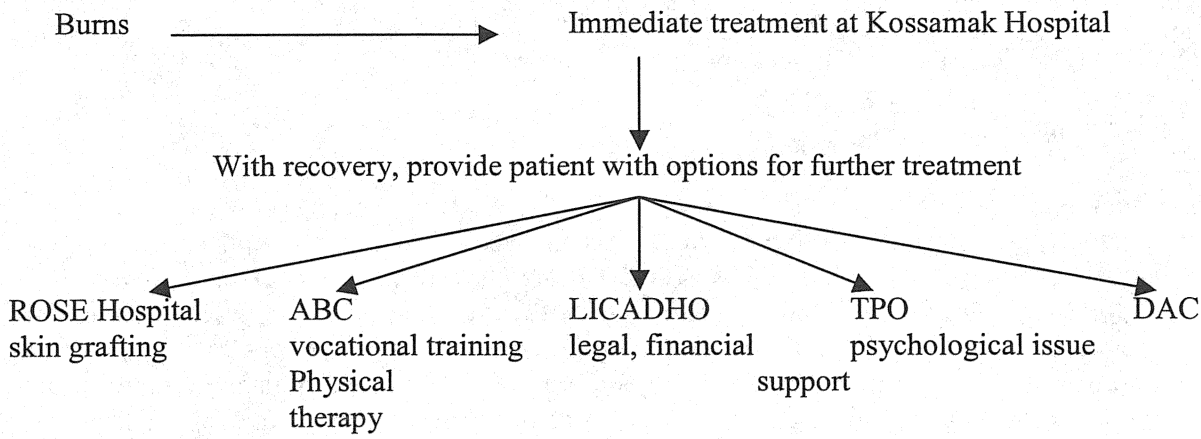
1) There was much enthusiasm among ABSs towards the development of an Acid Survivors Foundation akin to that found in Bangladesh. Such an agency could coordinate efforts taken by the local NGOs in addressing the complex issues facing survivors. This would include raising awareness of the issue to policy-makers and the general community, outreach to survivors, facilitating collaboration among NGOs and working within existing services to improve therapeutic options to ABSs. Independent of the creation of an Acid Survivors Foundation, the following is nonetheless recommended:

2) Increasing awareness about the issue of acid burns and its long-term impact among the NGO community in Cambodia through existing mechanisms of advocacy and action (for example by LICADHO, ROSE and Kossamak Hospital).

3) Outreach to survivors of acid attacks across the country, developing mechanisms to bear the economic costs of transporting and caring for them at appropriate medical and rehabilitative institutions.

4) Collaboration among NGOs to enhance the long-term treatment strategy. This concerted effort would greatly improve the opportunities available to the survivor for recovery and re-integration into society, and take away from the current stigma of seeking care. Such cooperation would involve informing the patient of relevant agencies that are available to

address their specific concerns. Thus, the hypothetical patient who has been blinded by an acid attack can take the following possible course:



Ideally, it would be helpful for the ABS to find all these therapeutic avenues under the umbrella of one agency. But until there is such an advocacy organization, the ABS may appreciate the existence and accessibility of existing mechanisms of short- and long-term care.

5) Improving existing services is critical to successful therapy for ABSs. This includes addressing the unique mental health concerns facing survivors within agencies like TPO; improving the medical resources available at Kossamak and ROSE Hospitals towards immediate treatment and reconstructive surgical opportunities; and improving accessibility to financial support, vocational training and long-term physiotherapy within agencies such as LICADHO, DAC and ABC. The principle of equal access to treatment should be the number-one priority in this situation, as there is evidence from our research of an existing support network that is arguably invisible to most ABSs.

Support Group

Our experience in conducting this study has demonstrated the benefits and importance of creating an environment in which acid burn survivors have the opportunity to interact with other ABSs. There is great therapeutic value to be gained in sharing stories, difficulties and insights for the survivors and their families. For this reason, we recommend the development and implementation of an "Acid Burn Survivor Support Group". This forum can be used as a means of sharing information about resources and treatments strategies. As well, it has the potential to provide significant psychological support through the development of friendships and skills to perform day-to-day activities.

Cooperation with other organizations may be sought in order to enhance the experience with field trips, seminars, and other such activities for the ABSs. The structure and organization of a

support group needs to be devised, possibly with help from organizations that are experienced with burn survivors, including the ABC, which facilitates support groups for individuals blinded by acid attacks.

We appreciate the logistical and financial difficulties that may arise from the development of support groups, including transportation difficulties among participants arising from economic or geographic limitations, but we are hopeful that the agencies supporting these groups will be able to receive funding to support this important initiative.

As an alternative to setting up a support group, we recommend the creation of a "buddy-system". This stems from the fact that there are some ABSs who, in the time that we've known them, demonstrated leadership and motivational skills that may be helpful to others who have a less positive outlook on their lives. In this situation, an acid burns patient seeking therapy at ROSE will have the opportunity to be paired with another ABS and thereby initiate therapeutic dialogue.

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APPENDIX 1

BURN QUESTIONNAIRE – June 4th, 2003
WHODAS Instrument

Interview Date:

Identification

1. Age
2. Living situation at the time of the interview
   → Are you living independently or in the community? In the hospital? Is someone taking care of you?

Demographics

1. Have you gone to school? [if **yes**] How many years of school have you done?
2. What is your current marital status: never married, currently married, separated, divorced, widowed, living with someone but not married.
3. What is your job? Paid work, self-employed [what do you do?], volunteer work, student, homemaker, retired, unemployed because of health, unemployed before health problems…
4. What do you do in one day?

Core Questions

How would you rate your overall health: very good, good, moderate, bad, very bad.

START QUESTIONS WITH:
In the last 30 days, have you had difficulty with:

1. Standing for 30 minutes
2. Walking for 10m; 200m; 1km
3. In the house:
   a. Cooking, carrying water
   b. Cleaning the house
   c. Washing clothes
   d. Take care of children
   e. Agricultural
   f. Carrying wood, agricultural work
4. Your work outside the house?
5. Concentrating on doing something for 10 minutes?
6. Washing your whole body? [if **very difficult**] Does anybody help you?
7. Getting dressed? [if **very difficult**] Does anybody help you?
8. Dealing with strangers, for example at the market, calling for a motodup…
9. Maintaining a friendship?
10. Generally, how much do these difficulties interfere with your life? [use flashcard]
11. How much difficulty have you had in learning a new task?

12. How much of a problem did you have joining in community activities in the same way as anyone else can?

Do these difficulties interfere with your life everyday? How many times in a week? How many times in a month?

How many days in a month are you completely unable to carry out your usual activities?

--------- NO SCALE, LET THE PATIENT TALK ---------

How has the burn incident affected your life?

How have you dealt with the pain? Itching? Scarring? Swelling? Fluid from the blisters? Have you used any medications, traditional treatments?

What has been helpful for you since the burn incident?

Clarify to the patient:

1. Have you gone to see a medical doctor before or after surgery at ROSEcharities?
    a. What did the doctor do that was helpful?
2. Have you gone to see a traditional healer before or after surgery?
    a. What did the healer do that was helpful? Not helpful?

Who has been helpful for you after the burn incident?

Who has NOT been helpful in your recovery?

Is there anything else that you'b like to tell us?

APPENDIX 2

APPENDIX 2